



# Measuring quality of life in macular disease: What use are utilities?

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**Abstract.** Utility values are often used as measures of quality of life (QoL). This study compared the suitability of time trade-off (TTO) values with the MacDQoL. Participants completed the MacDQoL and vision and health-related TTO questions by telephone interview ( $n=33$ ) or self-completion ( $n=100$ ). 38 members, unable to read large print, completed a short telephone interview, including MacDQoL overview items and TTO questions. *Results:* 100% completed the MacDQoL, 71% completed the vision-specific (health-specific=75%) TTO question, of whom 38% (42%) said they would give up no years of life for restored vision (perfect health). Among those who would give up no years for restored vision (perfect health), proportions of blind, partially sighted and not registered people did not differ from the entire sample. Respondents considered factors other than their QoL when responding. The MacDQoL average weighted impact score was sensitive to vision status ( $r=0.444$ ,  $p<0.01$ ), as was the MD-specific QoL overview item ( $r=0.426$ ,  $p<0.01$ ), but the vision-specific TTO utility value was not. *Conclusion:* The data support the validity of the MacDQoL but suggest that utility values provide no indication of QoL in people with MD. © 2005 Elsevier B.V. All rights reserved.

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## 1. Introduction

Increasingly, quality of life (QoL) is included as an outcome measure in clinical research and practice but there is little consensus about its definition and measurement [1]. Patient reported outcomes (PROs) of health status, functional status and psychological well-being have all been mislabelled as QoL and the interpretation of

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such findings can be misleading [2]. While those constructs *may* affect QoL, they do not necessarily do so. When measuring the impact of a medical condition on QoL we need to consider the impact of the condition on aspects of life of relevance to the individual concerned. The MacDQoL is an individualised measure of the impact of macular disease (MD) on QoL [3]. MD is a chronic, progressive and largely untreatable eye condition resulting in loss of central vision. The MacDQoL investigates individuals' views of the impact of MD on life domains commonly affected by MD and the importance of each domain to their QoL. Multiplication of impact score by importance produces weighted impact scores for each domain applicable to the individual. An average weighted impact score (AWI) is obtainable. Overview items measure (i) present QoL and (ii) the impact of MD on QoL. The MacDQoL has good face and content validity and evidence of good internal consistency reliability and construct validity [3].

Condition-specific PROs, have been criticised for not producing scores that are comparable across conditions, needed by health economists for analysis of the cost-effectiveness of interventions [4]. Utility assessment, using time trade-off (TTO) and other methods is often used to meet this need. Utility values are quantitative expressions of preference for given health states. The TTO method (where people are first asked how long they expect to live and then are asked how many of those years they would be willing to give up for a hypothetical treatment that would give them perfect health or perfect vision for their remaining years) has been used to assess QoL in several eye conditions [5,6].

In the course of a larger study relating to the equivalence of MacDQoL scores obtained using different completion methods, two TTO questions were included after the MacDQoL, one referring to perfect health and the other to perfect vision. The aim was to compare the relationship of the MacDQoL scores to vision status (registration as blind, partially sighted or not registered) with the relationship between TTO scores and vision status. Hypotheses included: (1) MacDQoL items would be more sensitive to vision status than the TTO questions. (2) Vision-specific TTO questions would be more closely related to vision status than the health TTO question. (3) If perceptions of health encompass vision status, health-specific utility values would be lower, indicating more years traded, than vision-specific utility values. (4) If utility values provide a measure of health status, there would be a correlation between the health-specific utility item and a self-assessment of general health.

## **2. Method**

### *2.1. Participants*

One hundred and seventy-one participants with MD were recruited from UK MD Society local groups.

### *2.2. Materials*

Introductory letter and consent form. Questionnaire with MacDQoL, TTO questions and a single item from the SF-36 to measure perceived health. All written material was designed for use by visually impaired people, printed in Arial font 16 bold.

### 2.3. Procedure

Participants were randomised to:

1. Self-completion of questionnaire on two occasions, or
2. Self-completion of questionnaire on one occasion and telephone interview completion on the other, half self-completing at time 1 and half completing by telephone interview at time 1.

A third group who wished to participate but who could not read large print were assigned to one short telephone interview consisting of the MacDQoL overview items, the TTO questions, and SF-36 health item. Data reported here were from the first completion of the MacDQoL for those participating fully, and from the short telephone interviews for group 3. Unsolicited remarks about questions were recorded verbatim.

### 3. Results

A total of 171 participants (mean age 79 years, 77.2% women, registered blind  $n=51$ , partially sighted  $n=60$ , not registered  $n=60$ ) completed either the short telephone interview ( $n=38$ ) or the full questionnaire (100 self-completion, 33 telephone). There were no differences in the ages of blind, partially sighted and not registered groups. There was no difference in proportions of blind, partially sighted and not registered participants in the self-completion and telephone interview groups. The short telephone interview group were predominantly blind.

All participants completed the three single items measuring general health, present QoL and MD-specific QoL. Only 128 (74.9%) completed the vision-specific TTO item and 123 (71.9%) completed the health specific TTO item. Of those who responded to the vision utility question, 49 (37.7%) reported being unwilling to trade any years for perfect vision (a utility value of 1, usually interpreted to mean perfect vision). Of those who completed the health utility question, 53 (42.1%) said they would be unwilling to trade any years for perfect health (a utility value of 1, usually interpreted to mean perfect health). For both utility questions, the proportions of people unwilling to trade any years did not differ with vision status. Means of the outcome measures are reported in Table 1.

Correlations (Table 1) indicated that the MacDQoL present QoL item was positively associated with better health. More severe visual impairment was associated with higher negative impact of MD on QoL. The vision utility value and the health utility value were positively associated with each other but with no other measures.

Table 1  
Correlations between outcome measures (Pearson's  $r$ )

Outcome measure (mean, S.D.)	General health (SF-36)	Health TTO	Vision TTO	MD-specific QoL	Present QoL	Vision status
AWI (−3.58, 2.09)	0.09	0.06	0.10	0.64*	0.30*	0.44*
Vision status	−0.18		0.10	0.03	0.43*	0.00
Present QoL (0.94, 0.86)	0.56*		0.15		0.10	0.07
MD-specific QoL (−2.05, 0.91)		−0.10			0.02	0.12
Vision TTO utility (0.71, 0.32)	0.05	0.73*				
Health TTO utility (0.74, 0.3)	0.170					

\* Significant at  $p<0.01$ .

Table 2  
Participants' responses to TTO questions

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*How many more years do you expect to live?*

'How do I know how long I will live? I could be dead by tonight'.

'That's a silly question at my age. It could be one, could be ten'.

'There is only one person who knows the answer to this and none of us has met Him yet'.

*How many years, if any, would you be willing to give up if you could have this treatment and enjoy perfect health (vision) for your remaining years?*

'If I were 10 years younger I would be prepared to give up some of my life for good sight but, at 91 years of age, I would not have the treatment'.

'At 93, I do not wish to respond'.

'Better to be around for the family even though incapacitated'.

'I would like to be around for long enough to look after my disabled brother'.

'There is my wife and family to think of. I could not ignore their feelings'.

'I do not think I could say. I have other health problems that affect my life'.

'I'm blessed with a wonderful partner. As long as we're together I would not want to give up any years. If I was on my own I might think differently'.

'Very few. Who knows? Blessed with loving family and friends, I cannot contemplate giving up any years'.

'I've had my life and I'm ready to die now. My husband is dead and I've had enough so I would not be bothered about having the treatment'.

'Nonsense and hypothetical. I'm amazed at an academic institution coming up with such a ridiculous question'.

'From the perspective of a medical person, they are too ridiculously hypothetical. In reality no patient would ever be asked that sort of question. I could not possibly answer them'.

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One-way ANOVAs were used to investigate the sensitivity of the measures to vision status. Both the AWI ( $F(2,130)=19.95$ ,  $p<0.0001$ ) and the MD-specific overview item ( $F(2,168)=18.08$ ,  $p<0.0001$ ) distinguished between not registered and both blind and partially sighted groups but did not distinguish between blind and partially sighted groups. Neither utility score was sensitive to vision status. Unsolicited comments highlighted difficulties with utility questions (Table 2).

#### 4. Discussion

This study found no relationship between TTO utility values and vision status. In contrast, greater negative impact on MacDQoL scores was associated with poorer vision status and hypothesis 1 is thus supported. There was no difference between utility values obtained from health-specific and vision-specific TTO questions. The health-specific TTO utility value was not associated with the SF-36 general health item. Hypotheses 2, 3 and 4 relating to the utility items were not supported, suggesting that the TTO items lack validity. There are several possible explanations.

The completion rate for the TTO items was lower than has been reported in other studies [5,6]. Our methodology differed from that used in some studies where participants are asked to consider standardised life expectancies, rather than state how long they expect to live [7], which may make the task less emotive. Utility values are often elicited during face-to-face interviews, and sometimes participants are asked to answer the questions while waiting to see the consultant, when they may feel reluctant to decline. In some studies visual aids are used to help participants understand the questions. In the present

study, the difficulty seemed to be not with understanding the questions but with willingness to answer. While participants reported no problems with the MacDQoL many found the TTO questions unacceptable.

The mean utility values for the vision-specific utility questions are comparable with values reported elsewhere [5,6]. People who completed the TTO questions and said they would not trade any time for perfect vision (38%) or perfect health (42%) were evenly distributed across the three registration categories, suggesting that the utility values lacked validity. Comments made by people who would give up no years indicate that the question does not measure QoL. Some responses (Table 2) better relate to the extent to which people *value* their life. Nevertheless, the MacDQoL data show that MD does impair QoL. Very elderly people found it difficult to consider giving up any time although MacDQoL responses indicate that MD impaired their QoL. It would appear that the TTO questions do not measure QoL, nor do they measure any other construct consistently in all participants.

The lack of difference between the vision-specific and health-specific utility scores reinforces our observation that most people do not perceive vision to be an aspect of health. A lack of relationship between health and visual status, reported elsewhere [8], brings into question the validity of comparing utility values across medical conditions when some utility questions refer to health and others refer to vision.

While the use of preference measures such as the TTO may be convenient for health economists, they cannot be regarded as valid measures of anything if people approach them differently, and if many people refuse to answer them. The data presented here suggest that the TTO has no validity for use in the MD population and may be unsuitable for other patient groups and elderly populations generally. TTO lacks face and content validity as a measure of QoL or of health status and did not show expected associations with vision status. Although TTO utility measures are commonly used to measure QoL, the present work indicates that they do not provide adequate measures of this important construct. The MacDQoL, in contrast, fared well on face and content validity, with the high completion rate suggesting that it is acceptable to participants. It is a comprehensive measure of the impact of MD on QoL that is sensitive to subgroup differences in the present study and elsewhere [3]. Studies now underway are investigating its responsiveness to change in vision status.

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